



Transcript - Financial Toxicity in Lung Cancer Care: How Patients Navigate the Hidden Costs

Colette Smith (00:00):

And that's when I found out my physician was out of network. Yeah. And the \$75,000 bill,

Annabelle Gurwitch (00:08):

Oh my God.

Colette Smith (00:09):

That followed. That followed the surgery.

Annabelle Gurwitch (00:10):

Oh yes. My Yes. God.

Ava (00:13):

Welcome to LCFA's, Living with Lung Cancer. Ask Me Anything podcast, where we have real conversations with people living with lung cancer. Learn from personal journeys and expert insights. Subscribe now and never miss an episode.

Annabelle Gurwitch (00:35):

This is Living with Lung Cancer. Ask me anything. I'm Annabel Gurwitch, your host today on this podcast we're having. The kinds of conversations that I wish I'd been able to have when I was diagnosed we're sharing practical strategies as well as talking about the emotional impact advances in science, community, building our challenges, and even how we're cultivating joy while living with lung cancer. If you're a patient caregiver, you belong here. Welcome. So today, uh, our guest is Colette Smith. Now Colette, you are an accomplished professional. You're a mother of five, you're a grandmother of two, and you happen to also be living with lung cancer. So we have lots to talk about. We do,

Annabelle Gurwitch (01:24):

We do.

Annabelle Gurwitch (01:25):

So, Colette, you and I have different experiences. You went through a surgery. I'm on a TKI. So between all of our experiences, we're gonna, uh, hash out the impacts today of our subject, which I'm gonna introduce with a little story. Okay? Yeah. Let's hear it. Alright. So a couple weeks ago I get this phone call and I see you on the phone. It's like on my cell phone. It's the number of the hospital. Like, I don't know about you, but whenever I see that number flash, like my life flashes in front of me, right. Because I've gotten every kind of call you can imagine, right? So, um, the phone is ringing, I pick it up and it's someone from a financial office and I'm like, uh, uh, uh, okay. And it's a very nice guy. And he says, um, hi, you know, uh, your doctor's office has identified you as someone who might want to support your oncologist's work.

(02:19):

Living With Lung Cancer: Ask Me Anything

And I'm like, uh, well, yeah. I really love my oncologist. I wanna support his work. And then I realize, oh my God, what he's saying is he wants me to make <laugh> pay your bill a big donation. Right? A big donation to the hospital. And I realized, okay, maybe I should not get so dressed up when I come to my appointments. 'cause clearly they think I'm someone who can make a big donation. And I am someone who just went on disability. So that is my way of introducing the topic today, which is the financial impact and what people call financial toxicity of living with lung cancer. So starting from the beginning of your experience when you were diagnosed with lung cancer and you had surgery, you were diagnosed at one A, right? So you were able to have a lobectomy.

Colette Smith (03:18):

Yes, I am what you call the anomaly with, um, stage one a diagnosis. Mm-hmm <affirmative>. And, um, the lobectomy, my financial, um, concerns

Annabelle Gurwitch (03:31):

Mm-hmm <affirmative>.

Colette Smith (03:31):

Um, began with my health insurance.

Annabelle Gurwitch (03:35):

Huh.

Colette Smith (03:36):

Um, on one plan, which was my plan where I was primary, um, my physician was participating, and I was well into my, um, doctor's visits before having to switch to my husband's plan. It made sense financially. And that's when I found out my physician was out of network and the \$75,000 bill.

Annabelle Gurwitch (04:01):

Oh

Colette Smith (04:01):

My god. That followed, that followed the search. So is was what did, what

Annabelle Gurwitch (04:06):

Did you do?

Colette Smith (04:07):

Ah, first of all, um, when, when I was going through that phase of my life where I was trying to figure out, you know, how to maneuver lung cancer Yeah. How to maneuver that diagnosis, finances are the last thing on my mind. Yeah. I just wanna get to a point where I'm feeling

Annabelle Gurwitch (04:24):

Better. Right.

Colette Smith (04:25):

Um, and, um, m months later, here comes the bill and Oh yeah, thank God I had some knowledge because that's the industry, that's

Annabelle Gurwitch (04:36):

The field. You work, you work in hospital, and I mean insurance

Colette Smith (04:38):

Living With Lung Cancer: Ask Me Anything

Administration, right? Yes. That's the field that I'm in.

Annabelle Gurwitch (04:40):

Uhhuh, <affirmative>.

Colette Smith (04:41):

And I know that when I go to a particular hospital that's in network,

Annabelle Gurwitch (04:45):

Uhhuh, <affirmative>.

Colette Smith (04:46):

And the authorization comes from the hos comes from my health plan through the hospital, there's no reason that I should be balanced billed by a physician who's not in network. So that gave me the tools to have a conversation with my insurance company and have them take a second look at that. I find that when insurance companies are aware that you have some knowledge,

Annabelle Gurwitch (05:14):

Uhhuh,

Colette Smith (05:14):

There's room for appeals and negotiations.

Annabelle Gurwitch (05:17):

You know what I've always heard, and maybe you can share this as an industry insider. I've always heard that if you challenge three times, uh, then you have a better chance of getting something changed because they expect to wear you down. So if it's a really big bill or it's some kind of unusual service mm-hmm <affirmative>. Uh, what I've, this is, is this any truth to this or is this just sort of like street wisdom?

Colette Smith (05:44):

It depends on the company's policy. Mm-hmm <affirmative>. Like for example, the company I'm with now, you have one chance, so you better give it your best

Annabelle Gurwitch (05:52):

Uhhuh <affirmative>.

Colette Smith (05:53):

So I would say gather all of your resources. Mm-hmm <affirmative>. Contact your physician

Annabelle Gurwitch (05:58):

Mm-hmm <affirmative>.

Colette Smith (05:59):

Have them even go through the appeals process on your behalf, provide all the medical notes and just prove your case on why it was medically necessary. So you give it your best shot. So

Annabelle Gurwitch (06:10):

You were able to prevail in that

Colette Smith (06:11):

Situation. Yes, I was,

Living With Lung Cancer: Ask Me Anything

Annabelle Gurwitch (06:13):

You know, what's really, um, I think challenging is, and I just wanna mention that, uh, if you're watching the show, you're listening to this show, you know, our community is really diverse. So we have people in rural areas who don't have as many advantages as if you are in a hospital, a bigger hospital system or a cancer center

Annabelle Gurwitch (06:33):

Mm-hmm <affirmative>.

Annabelle Gurwitch (06:34):

But I think one of the things that, um, your initial entry into the lung cancer world mm-hmm <affirmative>. That shows that, um, if you can immediately when you're diagnosed, look for if your hospital system has a patient navigator service, like their large hospital systems mm-hmm <affirmative>. Will have that. And at the end of this podcast today, we're gonna give some names of some organizations that can help. If you're independent, like if you're with an oncologist in a rural area and you don't have that kind of system available to you because you really need help sometimes in navigating this. And the sooner that you enter into, uh, some kind of, uh, conversation with someone about the finances, the better off you are. Because we don't, we don't, we're not able to always anticipate what is gonna be coming ahead of us. And the patient navigation systems that are in hospitals are typically there for you when you start treatment and not later in your treatment.

(07:40):

And that's an irony because you don't know what you're gonna need. I, I didn't assume that I would have as great a financial impact as I had had, or, or as you said, I, I just wasn't on my mind. But I also, I just didn't know what I was in for. It was so shocking that one of the first things that happened to me was, um, it was right after I started my TKI and I was having brain fog and I wasn't even aware of that. Mm-hmm <affirmative>. Uh, and I was so, I was such in, in such shell shock that, um, I live in California, it's midnight and there's a huge knock on my door and it's during the pandemic and I don't know what's happening. And, um, it's a guy who's got a weapon in his hand. He's got a billy club in his hand, and he's there to repossess my car.

Annabelle Gurwitch (08:41):

Mm-hmm <affirmative>.

Annabelle Gurwitch (08:42):

And, uh, I was in such a state of shock. And of course my kid, it just happened. So it happens that my kid was walking up into the driveway at the same moment as this scene is unfolding where this guy's yelling at me, I'm yelling, I'm crying, I'm yelling, I'm mm-hmm <affirmative>. Weeping on the ground and he repossessed my car. I had thought that I was keeping track of things financially, but I wasn't. And that was really devastating. I felt. So I've just been diagnosed with lung cancer. I'm just on this new medication and now I have failed to handle my finances for myself and my family. It was like, I just, that was a really low moment. So I think if you're just been diagnosed, try to plan ahead a little bit and see how you can get set up with different kinds of resources, uh, that can help you. And you know, one of the things that, um, I, I'm telling the story is that, you know, when people wanna help you, a lot of people rallied around me and, uh, people wanted to help, but they didn't know how to help. Uh, one of the ways you can help people sometimes is maybe someone's more organized. Maybe they can't give money, but they can help you organize your finances or that kind of thing. And, and it's great that you

Colette Smith (10:14):

Living With Lung Cancer: Ask Me Anything

Had that support. Yes. As I'm listening to your story, you're taking me back to mine. Um, my husband was diagnosed with prostate cancer two years before I was diagnosed with lung cancer.

Annabelle Gurwitch (10:29):

Oh my

Colette Smith (10:30):

Gosh. And I remember the parents at my son's school rallying together. 'cause one of the things that suffered, we didn't have meals. I didn't have time to prepare meals.

Annabelle Gurwitch (10:40):

Yeah. Yeah.

Colette Smith (10:41):

And instead of creating meals and dropping them off, they did all of the grocery shopping for me, um, drops, um, the groceries off or even had them delivered. And, um, we got through that point and just when I thought, okay, so we are over a cancer scare, let's move on with light

Annabelle Gurwitch (11:00):

Right

Colette Smith (11:01):

Here I come with lung cancer and it, it was like a vicious cycle. Wow.

Annabelle Gurwitch (11:06):

Yeah.

Colette Smith (11:07):

And a different set of financial challenges. Work uhhuh taking time off of work.

Annabelle Gurwitch (11:15):

Yeah.

Colette Smith (11:15):

Running out of vacation days, not being paid. And even at one point, Uhhuh,
(11:22):

I didn't have the resources to take my son to school. I was sick and unable to travel. And he was a, uh, a younger boy who could not travel on his own to get to school. Right. And I was brave enough to have the conversations with the administrators at school and his teachers, and we brainstormed and finally what we came up with, well, why not just have a cab service come pick him up in the mornings and dad can pick him up on the way home. And, um, that was a great help. I never knew those resources were available to me. And I had the courage to say, here I am, I'm in need. What can you do to help?

Annabelle Gurwitch (12:01):

Wow. And so that was paid for by your community, you said? Yes. You know, that, that just is just an amazing thing. I mean, um, that again is one of those things that I think we don't think ahead to anticipate of what am I gonna need? Or also how can I help someone? And when you say that, I'm reminded that yeah, I, I've done things in the past when other people have, when people in my community have been sick, I've delivered meals. I honestly hadn't thought about, um, offering to drive someone's kids somewhere. I mean, these are the kind of out of the box ideas that I wanna share on the

Living With Lung Cancer: Ask Me Anything

show. Um, organize someone's finances. 'cause people think, how can I help? If you're watching this, you're listening to this and you're a caregiver, or you're a friend of someone who's been diagnosed.

(12:57):

Maybe it's that kind of thing. Because these are the things that are the, the sort of the, the, um, daily mm-hmm <affirmative>. Activities that really fall away when you're diagnosed with something so serious as such a serious impact. Um, you know, something you just said, Colette, that I just, these conversations about money are really hard to have, you know? Uh, and so to be able to actually also ask for help and not feel like a failure, I mean, in my opinion mm-hmm <affirmative>. And this is a whole other discussion we're not gonna get into, but it, you know, if you think about in the larger sense, you know, I honestly, I feel it's a system that fails us that we don't have that kind of infrastructure to help people. And so we take it unto ourselves to feel like, oh, I'm a failure if I haven't planned for this. But I think, you know, there's, um, only so much planning we can do. And I mean, you and your husband were both working. I mean, we are people who thought we had everything planned, and then really big things happen that we are just, uh, we're impacted even more than we could possibly prepare for. And there's not infrastructure, I think, I think people feel it's their failure. And I wanna share this from each of our perspectives to say it. It's not, it's okay to talk about it, you know?

Colette Smith (14:29):

Um, not at all. Um, here's my thoughts on that.

Annabelle Gurwitch (14:33):

Yeah.

Colette Smith (14:33):

A closed mouth never gets fed. Hmm. And these are conversations I've had with my, um, my treating physicians.

Annabelle Gurwitch (14:41):

Mm-hmm <affirmative>.

Colette Smith (14:42):

I talk about, um, challenges taking time off of work, why can't we schedule the scans and the visits and whatever other specialists I need to see Yeah. On the same day.

Annabelle Gurwitch (14:57):

Yes.

Colette Smith (14:57):

And my treating facility has been able to do that for me. So had I never had those conversations

Annabelle Gurwitch (15:05):

Right,

Colette Smith (15:05):

We never would have sought those solutions.

Annabelle Gurwitch (15:07):

You know, that's a really good point you bring up because one of the things about, uh, patient advocacy, which is something you and I are both involved in, is every time one of us has the courage to bring up this topic with our doctors and our facility, it has repercussions for everybody else who's getting care.

Living With Lung Cancer: Ask Me Anything

Because I know, you know, I am treated at, at, at a really large hospital. I'm treated at City of Hope. I don't mind saying it's all cancer all the time. They're so busy scheduling so many people, they're not thinking about that. It's top of mind. But, you know, um, there's been some really interesting developments recently. I know that, um, I think it's McMillan hospital system has started a new thing in their tumor board, and that's the kind of thing where they look at a patient, uh, their patients mm-hmm <affirmative>. Um, uh, health history and the toxicities they're experiencing with the treatments they're on

Annabelle Gurwitch (16:10):

Mm-hmm <affirmative>.

Annabelle Gurwitch (16:11):

And they think about whether or not, you know, which, which line of treatment is right. Financial toxicity has just been added as one of the categories they are evaluating. Now they've done this in response to the new changes in Medicaid, um, when actually this has been going on for a long time mm-hmm <affirmative>. Uh, but, uh, this is one of these really big issues. And I, and I want to bring up this, uh, one of my mentees, uh, you know, I, our c is, is so tight part, partially because lung cancer used to be something people would just die from. Now we are living longer and we are underfunded. And there's also less information about it the way that there's a lot of information about breast cancer mm-hmm <affirmative>. So definitely we all talk to each other. I have people that I mentor. I don't want anyone to go through what I went through, which is, when I was diagnosed, I knew no one with lung cancer.

(17:09):

And for six months I just had all the wrong information. I didn't know about any of the advocacy. I didn't know, I didn't know how to connect to anyone. I'd know information. So, uh, I mentor people and one of my mentees hasn't told her doctor that she hasn't told her employers that she's in treatment for stage four lung cancer. So interesting because this could never have happened in the past before we had biomarker targeted therapies. She's able to be on one of those therapies so she can work. Um, although she has, she is affected by the treatment, she has side effects. But her doctor has wanted to put her on a combination therapy, a chemo, and a TKI. She doesn't wanna do that because that would really take her out of work. She'd have to miss more work. And she is one of us who has difficulty talking about finances.

(18:12):

So she hasn't told her doctor. So she's sort of at odds with her doctor on what treatment they should follow, because she hasn't said, I really need my work and I can't miss any work. And this is where, you know, the opportunity of these precision personalized medications become so that all the considerations are different than in the past when it was like very intense chemo or surgery. And that's it. Now, all this nuance, it really asks us to have more nuanced conversations with our doctors mm-hmm <affirmative>. Um, but it's not easy. But so as you said, you know, um, you know, asking to be scheduled on the same day for work, I just don't think in the past, because there wasn't the thought, you'd still be working mm-hmm <affirmative>. You know, your life would just be, be so impacted in a way that you wouldn't be able to work if you were just on this really extreme chemo. Now we have to help train these institutions and doctors to be thinking about our quality of life, and it's not easy.

Colette Smith (19:22):

Living With Lung Cancer: Ask Me Anything

So, um, something you said Yeah. Take me back to my experience at work mm-hmm <affirmative>. And I understand this woman's hesitancy in sharing her diagnosis. Yes. And maybe even her treatment plan. Yeah. And what doctors have planned for her, even though this may be her best fighting chance.

Annabelle Gurwitch (19:39):

Right.

Colette Smith (19:39):

I think it's natural to think about work and what it means and potential absences. I had an experience with my job, and we think that FMLA laws are there to protect us and to protect our jobs. I believe it's just, in my experience, it's been a facade. I worked for an organization mm-hmm <affirmative>. In fact, it, uh, a group of, uh, medical facilities

Annabelle Gurwitch (20:18):

Mm-hmm <affirmative>.

Colette Smith (20:19):

For over 16 years

Annabelle Gurwitch (20:21):

Mm-hmm

Colette Smith (20:22):

<affirmative>. I went through the, um, cancer journey with my husband and taking time off of work.

Annabelle Gurwitch (20:28):

Right.

Colette Smith (20:28):

And then here I come with my diagnosis, to which my director says, not again, not more absences. Oh my God.

Annabelle Gurwitch (20:40):

<laugh>. Oh my God. Now I just have to ask you, were you in person when that happens

Colette Smith (20:44):

In person?

Annabelle Gurwitch (20:45):

And, and what is the reaction that, how did you mask any, like, are you kidding me? Is that your, how did you do that?

Colette Smith (20:55):

I don't know if I did mask it,

Annabelle Gurwitch (20:56):

Huh? Mm-hmm

Colette Smith (20:57):

<affirmative>. I was flabbergasted. Yeah. And I wanted to say, oh, what do you mean? And at one point I was told I have a job.

Annabelle Gurwitch (21:06):

Living With Lung Cancer: Ask Me Anything

Mm-hmm <affirmative>.

Colette Smith (21:07):

Um, and she relies on me to get that job done. So long story short,

Annabelle Gurwitch (21:14):

Yeah. Mm-hmm <affirmative>.

Colette Smith (21:15):

Three years where I went through an ordeal after absences, um, explaining, said absences, even though I had this FMLA law

Annabelle Gurwitch (21:29):

Mm-hmm.

Colette Smith (21:29):

To protect me

Annabelle Gurwitch (21:30):

Mm-hmm <affirmative>.

Colette Smith (21:31):

Ultimately I lost that job. However, there's a silver lining to this story. Mm-hmm <affirmative>. There's always a

Annabelle Gurwitch (21:39):

Silver lining to your story.

Colette Smith (21:41):

God, I challenged the city of New York

Annabelle Gurwitch (21:44):

Uhuh,

Colette Smith (21:44):

And it was found that I was discriminated against because of my disability mm-hmm <affirmative>. With my lung cancer diagnosis. So this is a lesson. Yes. This is a lesson. And it's, it's not, it's not, it wasn't an easy task to do that I had to put on, um, a suit of armor. To get brave in order to take on that battle. But it's one that I felt confident that I could win because I knew that I was not treated fairly.

Annabelle Gurwitch (22:13):

Right. You know, um, people talk about, you know, battling cancer. I, you know, I'm, I'm a writer. And so I did a piece for the Washington Post about a situation I got into with a, a third party insurance adjuster in my, uh, um, PBM Pharmacy Benefit Manager, who, um, I woke up one day and discovered they had taken over \$4,000 out of my account to pay for my, uh, targeted therapy, which was a mistake. 'cause I had signed up with my, um, patient advocate program through the pharmaceutical and through my insurance. It was supposed to not be any charge. Mm-hmm <affirmative>. Um, but I titled that article, uh, tackling Cancer, battling Insurance Companies. Uh, sometimes one of the hardest things we're doing is fighting for our life in terms of our jobs and our insurance. And, um, it's really great to hear that you prevailed. I wanna ask you a question for people who are listening or watching this. Um, how did you get the knowledge to know how to, what kind of resources did you turn to, to figure out how to do that?

Living With Lung Cancer: Ask Me Anything

Colette Smith (23:42):

At the time, we did not have a copilot or chat GPT. It was Google. Yes. I did a lot of research. Uhhuh, <affirmative>, I did a lot of research. Mm-hmm <affirmative>. I documented if I had conversations with my director or hr, I would follow up with an email. Documentation is very important.

Annabelle Gurwitch (23:59):

Mm-hmm <affirmative>.

Colette Smith (23:59):

And it's important to actually try to resolve the issue internally, which is what I did. Uhhuh <affirmative>, I took it to hr and I would step it up a notch each time I took it to the president of the organization, I took it outside of the organization mm-hmm <affirmative>. To our parent company. And, um, and that created the paper trail that I needed.

Annabelle Gurwitch (24:21):

Right.

Colette Smith (24:21):

Um, I would co, I would, every communication, I would say I'm, I believe I'm being treated unfairly because mm-hmm <affirmative>. Of my, um, my, my illness. I'm looking to resolve this. I would restate my position. I enjoy my job. I will continue to do the job

Annabelle Gurwitch (24:41):

Right

Colette Smith (24:41):

To the best of my right abilities while I'm at the job. And just document and be very specific.

Annabelle Gurwitch (24:51):

Mm-hmm <affirmative>.

Colette Smith (24:52):

In your documentation

Annabelle Gurwitch (24:53):

Every week on living with lung cancer, ask me anything. Podcasts, we explore questions that matter most to people living with lung cancer. We talk about new treatments, everyday challenges, new research, and we share the stories of patients and caregivers who are finding hope and strength. If you want these insights delivered straight to you, subscribe on any of the podcast platforms or go to lc-america.org. And if you know someone who could use some understanding or encouragement or both, share this program with them. And don't forget to subscribe. Now, back to our conversation, I've had to learn more about, I thought from a career in show business mm-hmm <affirmative>. I knew how to advocate for myself, but I've had to learn even more about that. And I think part of that is, um, an institutional change of framework of mind for us when we, there was a, a generation maybe before us

Annabelle Gurwitch (25:52):

Mm-hmm

Annabelle Gurwitch (25:52):

Living With Lung Cancer: Ask Me Anything

<affirmative>. Who had a very specific way of dealing with healthcare. So you did whatever your doctor said to do mm-hmm <affirmative>. And you, you, you, you felt so unempowered and you just, you just listened and whatever you, you say doctor and what, and, and you just felt like you couldn't, um, have a voice. I know. My grandmother, you know, is in that generation for sure. And I'm not saying don't do what your doctor says. Mm-hmm <affirmative>. But I think that what we are seeing now is we really need to have a patient provider partnership.

Annabelle Gurwitch (26:28):

Mm-hmm <affirmative>.

Annabelle Gurwitch (26:28):

Um, and also in terms of these things, like whether or not you're in a protected class of employment, whether or not you're gonna challenge your health insurance, we have to advocate for ourselves. Definitely. The system is so big and convoluted, and I feel like I am required by the, like, universal patient mandate to say it's a kafkaesque system. I mean, there's no other way to describe it, you know, it's just you feel like you're in a maze. And, and I wanna also remind people that when we hear Colette say that you challenged and you were successful, you know, you're modeling behavior. And we're also letting these administrations know that, you know, we are empowered. And I think, uh, we, we, there's a feeling sometimes we can't do it. But, um, and, and I think, you know, friends can sometimes help as well mm-hmm <affirmative>. But I think we can rise to that occasion in your, you know, great model or of that. One of the things I actually heard recently that I thought was some good advice was if you feel uncomfortable saying something in person to your doctor,

(27:47):

Try to identify someone else on the care team who you do feel comfortable speaking to. Or maybe there's a different way of addressing something. Maybe you feel more comfortable in an email or on the phone as opposed to in person. Mm-hmm <affirmative>. I sometimes find I get intimidated when I am in the hospital setting mm-hmm <affirmative>. And I'm in an exam room, because I might be there also to get information on whether or not there's been progression. So I've got all that going on at the same time as I might wanna talk about finances. That's a lot. I think we have to try to, um, separate

Annabelle Gurwitch (28:27):

Mm-hmm <affirmative>.

Annabelle Gurwitch (28:27):

These kinds of conversations. Um, so, uh, we're coming to the end of this episode on financial toxicity. I want to just ask you, Colette, is there anything else, is there any other strategy or situation that you wanna bring up that was unanticipated?

Colette Smith (28:48):

I, I wanted to mention, um, one other thing as you were talking about advocacy

Annabelle Gurwitch (28:54):

Mm-hmm <affirmative>.

Colette Smith (28:54):

It's important as a patient to never forget the sound of your voice. Our voices are important. And if there's something about our care, about our financial circumstances that troubles us, find an ear. And the first set of ears that you find may not be the ears that will listen and want to take action or assist you

Living With Lung Cancer: Ask Me Anything

with taking action on, on your behalf. But, um, it's important to pursue because your health is at stake, and our health is important, but never forget the sound of your voice.

Annabelle Gurwitch (29:36):

We know people in our community who have gone through their 401 Ks <laugh> and, uh, Dr. David Carbon, uh, who's been one of the greats, uh, oncologists, long time oncologists in lung cancer. Um, not long after I was diagnosed, uh, when I still didn't know really. I just had started my biomarker targeted therapy. He was concerned about me because I really, I had been told, you know, when I was diagnosed, what my doctor, my first oncologist said was, we'll do the best we can for as long as we can. I really wasn't sure, you know, what, how long I'd be alive. And he said, Anabel, there's good news and bad news. Uh, the good news is that people are living longer and the science is changing, and the bad news can be. He said, I, uh, I gave a patient some news recently. I said, I have great news, and that is that your lung cancer has disappeared.

(30:47):

This is an early stage diagnosis mm-hmm <affirmative>. And he said, oh, shit, I spent all my money <laugh>. So, you know, like we, we, uh, uh, the, the great news about precision medications is that we are living longer, but that actually requires all kinds of financial planning. And that gets to what I wanted to bring up, which is that the voice that I actually turned to was another patient. Um, because I really didn't know who to talk to. I think we also have ideas in our mind of, you know, what does that mean? Oh, you know, to go on disability like that, that had a profound effect on my identity. I had to sort of work my head around that, that that was not going to be the first thing that's part of my identity. Just like lung cancer isn't the first. I'm still me. I'm still, uh, my, I'm still a, a, a, a writer, a community activist. I'm still a mom. I, you know, I, I, I am, this is part of my identity, but that doesn't, it's not the totality of my identity. And I think that's a concern for people when they talk about finances, that this is something that's gonna mark them, you know, in the eyes of other people I'd like to see, I'd like to see that stigma lessened.

Colette Smith (32:15):

Mm-hmm <affirmative>. Um, finances definitely, um, play a role in defining who we are. And it creates some limitations in what we can do,

Annabelle Gurwitch (32:25):

But

Colette Smith (32:25):

Yes. But it's not for sure. It's not our totality.

Annabelle Gurwitch (32:28):

Yeah.

Colette Smith (32:29):

Just like cancer and lung cancer is not our totality. Um, we don't know what we don't know, um, on this journey. And, um, it's something that we figure out every day.

Annabelle Gurwitch (32:42):

Yeah.

Colette Smith (32:42):

And I have a community of other lung cancer survivor friends

Annabelle Gurwitch (32:48):

Living With Lung Cancer: Ask Me Anything

Mm-hmm

Colette Smith (32:48):

<affirmative>. And I rely on them a lot. Um, even as a 10 year survivor, I rely on that group a lot. Um,

Annabelle Gurwitch (32:56):

Yeah. You know, it's funny, uh, I think even as a 10 year survivor, that's interesting that you say that. 'cause you know, I'm five years into this. This is, this is an ongoing concern that affects our lives as we know, lung cancer can come back, but also we're dealing with, you know, the effects of the disease. And we'll talk about that. Mm-hmm. In another episode, I wanna just give a couple of organizations names. This is, that's my lung cancer cough. Mm-hmm. <laugh>. Um, I wanna give a couple names of organizations, uh, that people can turn to for resources. Triage cancer has a tremendous amount of resources. Uh, patient Advocate Foundation is one, cancer Care is another. We're gonna have a list at LCFA also at my website, annabellegrich.com. I have resources. So, um, I hope that, uh, people listening and watching out there have, uh, felt like they've been alone in the room right here with us, Colette. And I urge everyone to connect with the community and raise your voice. And, uh, if you like this podcast, start subscribing to it. Leave a review and find us on the web. And thanks for listening. And thanks for coming Court. Oh,

Colette Smith (34:29):

Thank you for having me,

Annabelle Gurwitch (34:29):

Colette. Thanks for listening to Living with Lung Cancer. Ask me anything. I'm Annabel Ger, which if today's conversation helped you follow, subscribe, share this episode with someone who might need it together. We can change the way we talk about lung cancer. And if there's a lung cancer related topic you want us to explore, let us know in the comments. Find out more@lcfamerica.org. You can find me on socials or at my website, annabellegurwitch.com.

Ava (34:59):

Thanks for watching and listening. Your support helps these stories reach more people. Subscribe to the channel, click subscribe to catch every new episode.